

# The Experience of a Buddhist Home Care Service in Australia

■ Ven. Pende Hawter

(synopsis of the talk to be given by Ven. Pende Hawter at the hospice conference in Taiwan at end November 1998)

The Karuna Hospice Service is a Buddhist-based home-care hospice service that was started in 1991 in Brisbane, Australia by Ven. Pende Hawter and others at the request of the Tibetan Buddhist master, Lama Zopa Rinpoche. The service has quickly developed into a mainstream provider of home care hospice services in Brisbane, and is partly Government funded. The care team comprises a group of specialist palliative care nurses, counsellors, spiritual care staff, volunteer coordinators, and is backed up by a palliative care physician. A large team of trained volunteers play a significant role in family support. The care team is backed up by a dedicated team of paid and volunteer administrative staff. Underlying the compassionate care offered by the Karuna team is the depth of knowledge about all aspects of death and dying offered by the Tibetan Buddhist tradition. This talk will discuss the experiences of the Karuna Hospice Service in its first 5 years of operation, and will outline some of the basic Buddhist principles concerning death and dying under which the service operates.

# HOSPICE AS SPIRITUAL PRACTICE

■Dr. Rosalie Shaw

## INTRODUCTION

Many people have asked me what the topic of this talk is to be. When I tell them that I am speaking on hospice as spiritual practice, most of them assume that I am going to talk about giving spiritual care to our hospice patients.

This is not what I want to talk about today. Instead, I want to explore with you how working in hospice deepens spiritual life and to talk about some of the many challenges faced in the encounter with people who are dying and with those who are grieving the loss of their loved ones.

I am by training a doctor, a nurse and a teacher. For the past eighteen years I have been working in the field of palliative care. Today I am going to talk about how this experience has challenged me.

## MY JOURNEY

I came into this work because of Elizabeth Kubler Ross. When I read her books I knew that she was writing about real people with real pain. She was uncovering what had been hidden. No one else had said dying people need us to hear them". No one else had said dying is a process during which denial, anger and bargaining are normal and acceptable." No one else had said that dying people are also grieving - grieving for the loss of their own lives. I admired Dr Kubler Ross' courage in opening our hearts and minds to this pain.

Thus began my journey. First I travelled across Australia to hear Dame

Cicely Saunders speak. I introduced myself to her and told her that I wanted to do this work. I expected her to welcome me, to be pleased that another doctor wanted to join her. I expected her to offer to train me so that I too could become a great palliative care physician. Instead, when I asked her what I should do, she replied, must go and do it!" What a let down! How could I do it when I did not know what to do? How could I care the dying without experience? But it was good advice. It meant that I had to grapple with the issues myself. I had to take responsibility. I had to become my own teacher, not relying on others.

In 1981 I persuaded the Medical Superintendent of my hospital to let me start a palliative care unit. Initially, I had no resources, no staff, only the good will of some of the doctors and a conviction that this was important work.

As I was referred patients, these patients became my teachers. They responded to my fumbling attempts to relieve their pain. They gave me love and taught me compassion. Day after day I grappled with what to say and what to do. The only thing I could offer was my intention to be honest. If I did not know the answer to their questions, I said that I did not know. If I said I would come to see them, I came, even if I could not get there till midnight. If I said that I loved them, I meant it.

## CHALLENGES AND DISCOVERIES

In those early years, hospice presented me with many challenges. I did not know how to cope when I was unable to relieve suffering. I found it difficult to respond to angry relatives. When I was exhausted I resented having to get up for the third and fourth time to answer the pager when on call at night. I tried unsuccessfully to balance the demands of family life against the constant crises - those urgent cries for help which could not be ignored because by tomorrow it may be too late.

But in hospice I discovered that spiritual practice is about becoming more

truly oneself, about dropping all pretence, about acting out of the present moment. Only when we are truly present to our patients are we aware enough, alive enough, awake enough to be able to recognise the uniqueness of each person, to be able to ignite that spark of love which heals pain.

## LISTENING AND HEARING

Each person has a story. It is the story of their journey. And hidden in that story is the seed of their pain, and of their joy. Let me tell you a story.

Many years ago when I was in charge of the palliative care unit in Perth, I heard about a lady who was being cared for at home. Her pain was totally out of control. I was asked to admit her to the ward. I dreaded meeting her because I did not know how I could help. I knew that she was already taking maximal doses of all the drugs that I could use. The day she was admitted I heard her screaming as she was wheeled down the corridor. When I went to her side she clutched me and said, "Help me! help me!" I asked the nurses put her to bed and to give her an injection which would sedate her for a few hours. Later that day I went and sat at her bedside. She pleaded with me to kill her, saying, "please Doctor, give me an injection to end it all!"

I waited a moment and then said to her, "If you feel that your life is now over, tell me about this life. Tell me what it has all been about."

She looked surprised and then began to tell her story. She was now 62 years old. When she was a young girl she had a lover. She became pregnant. When she told her lover that she was to bear his child, he abandoned her. She felt betrayed. She had not told anyone else about the pregnancy. She did not know what to do.

What she did do was to seduce another young man and passed off this pregnancy as his child. She never told him that he was not the father of the child. She never told her daughter that this man was not her true father. This man had since died.

For a long time she sobbed out her shame and her guilt.

Later that night I came back to see her. There was no pain. I reduced her medications. Next day there was still no pain. I reduced her medications ever further. The following day she returned home to her daughter. She died that night peacefully and without pain.

This lady taught me that by telling her story she was able to release her pain. She also taught me how important it is to listen. So often in trying so hard to do and say the right thing, we fail to make a real encounter. Hence we fail to hear what the patient is trying to tell us.

## TRUTHFULNESS

In hospice I also learned that listening is not just about listening to the words that the patients say. Listening is also about hearing what is behind what is being said. When patients ask questions, often I find these questions threatening because they are questions for which there are no clear answers.

When patients ask why is this happening to me?" they do not usually expect an answer. In fact, if we give an answer we distract them from the process of looking at their own lives and from coming to their own awareness of who and what they are. When patients ask why is this happening to me?" they are telling us something, not asking. They are telling us that they are exploring the deep mystical questions of life. The appropriate response is an acknowledgment of this and a reassurance that we all grapple with these questions.

Hospice forces us to confront the reality that life is unpredictable and that death comes to us all. By contrast, the medical model tends to take a mechanistic view of the body. It considers that the task of the doctor or the nurse is to diagnose what the problem is and to give treatment which will solve the problem. It is then assumed that the problem will not recur. This model does not work well for chronic diseases. It does not work at all if the patient is

dying. When the patient is dying, symptoms recur, symptoms get worse, new symptoms appear. If the doctor sees himself as someone whose main role is to fix symptoms, he will be overly aggressive in his treatment, continually frustrated and will be seen by his patients and their families as having missed the point completely.

Most dying patients sense that life is coming to an end. This is true even for those who are not fully told the diagnosis and prognosis. Most patients do not expect the doctor to be able to solve every problem. They know that pain, nausea and breathlessness may be an inevitable accompaniment of the dying phase. They want relief if this is possible, but if this is not possible they do not want the doctor to be continually seeking another drug, another course of chemotherapy, another treatment, unless there are realistic chances of success. Most do not want their hopes bolstered with false promises. Instead, they ask that we accept the inevitable and travel this journey with them, continuing to show that we care and acknowledging their courage and their integrity.

Yet it so hard for some doctors to do this. Doctors feel impotent and incompetent if they cannot do something. Their medical training has prepared them to do something to the patient but has not prepared them to be with the patient.

Patients are vulnerable and they are very sensitive. They are aware when we are not telling the truth. They are aware when we are uncomfortable. They are aware when we are being hypocritical. They want us to be ourselves, with all the uncertainty, pain and confusion that this means. They want to hear the truth spoken, gently.

Let me tell you another story.

I first met Ray one Wednesday afternoon. The nurses in the outpatient clinic called me and asked me to come. They said that they wanted me to see "a man with a suitcase and half a face".

Ray was a simple man. He had no family. He made a little money selling

cotton candy from a stall at fairs. He was a "airy floss" man. For the past two years a tumour had been growing on his face. He had been to a herbalist who had told him that he could cure it. But the tumor had continued to grow until now it had invaded his nose and his right eye. He told me that he had not known whether to kill himself or to give himself up". By this he meant to come to hospital for medical treatment". That morning he had made the decision to come to hospital. I examined his face and told him that he had a cancer that could not be cured but that I would get a surgeon to tell us what could be done. I also said that no matter what the surgeon said, we would look after him.

He was admitted to the ward. Investigations were done and he was transferred to another hospital for an operation.

I was at a meeting when the surgeon rang me. He told me that he had Ray on the operating table and that he had discovered that the cancer had invaded across to the other side of the face.

I must take out both his eyes", the surgeon said.

So!" I said. You must wake him up and send him back."

Later that day I went to see Ray.

Have you heard?" he said.

Heard what?" I asked.

What I will go blind and die".

There was a long moment of silence and then I said, So, Ray. I do not think that you will go blind."

Without any further explanation he understood. He knew that he would not live long enough for this to happen.

## CONSEQUENCES

It was from that day that the magic began. Ray became one of our hospice family". The nurses showered him with love and concern even to the extent of dressing him up and taking him out of the hospital when their shifts had finished. Ray was very surprised and very touched by this care. He watched what we were doing with other patients. He talked to other patients' relatives. He asked questions about our funding and about our plans for the future. And he decided that we needed help. He wrote a letter to the premier of the state. This was just a handwritten note on a piece of paper - no letter head, no typing. The note said that the premier should see what we were doing, that we needed help and ended with the words, please come soon. My time is short."

The premier did come. He came on an unofficial visit at 7 o'clock one morning. He sat on one end of the sofa. Ray sat on the other with bandages over the gaping hole in his cheek. They chatted for a while and the premier then turned and asked me, what do you need?"

Subsequently we received a special grant to build our 22 bed unit and to staff the unit for two years. Without Ray this may never have happened.

During the early years of development, I often thought that what I was doing was having no effect. Both in Perth and in Singapore, we all seemed to be putting in many hours of effort without any increase in resources. No one seemed to know or care what we were doing. But what I have learned is that every action has an effect. The kind word, the smile, even just stopping at the bedside of a hospital patient who is vomiting - all these actions ripple out into the universe, changing the way things are for ever. Maybe it provides a model of caring for other staff, or it gives courage to another patient to continue treatment or perhaps it opens a door of opportunity which was previously unseen.

**Gandhi said it so well:**

It is the action, not the fruit of the action, that is important. You have to



do the right thing. It may not be in your power, may not be in your time, that there will be any fruit. But that does not mean that you stop doing the right thing. You may never know what results come from your action. But if you do nothing, there will be no result."

But when I was exhausted, disappointed and sometimes very frustrated, it was sometimes difficult to believe that there would be a result, that our dreams would become a reality. All we had was intent. We had to hold the vision that we could provide loving care and act without attachment to the outcome. All we could do was to focus on the patient, asking ourselves what can I do for this particular patient at this particular moment?"

And slowly to my amazement the resources came - the funding, the staff, the buildings. If I had been asked to plan I could not have imagined that so much would happen in so short a time. The services grew out of those actions when our focus was on each patient. And the simplest men and women were the greatest agents for change. Ray who was the catalyst for the palliative care unit in Perth, was with us only a few short months. Before he died he bought a small camellia tree which we planted outside the window of his ward. We had not noticed that it had a bud, but on the morning of his death there was a single flower in full bloom.

## SUFFERING

In many countries, the hospice palliative care movement has now reached a mature stage of development with many organisations providing care. However, I am concerned that the original vision has been lost to some degree. There has been a subtle shift, from focus on the whole patient, to focus on alleviating physical symptoms. The medical model has reasserted itself at the expense of meeting other real needs of the patients, and at the expense of making the healing encounter.

My next story is about how difficult to enter into the suffering of our

patients. This is the story of Jeanette who was the mother of a seven year old boy. She loved this son very much. She knew that she was going to die but she did not want to leave. As her condition worsened, her body began to decay. She had lost a great deal of weight and was now just skin and bone. She developed holes from the tumour to her skin. These were discharging foul fluids. She had ulcers in her mouth. She could not swallow. She was in severe pain. She was so weak that she could not lift her head from the bed. Each day I saw the situation getting worse. I was distressed that her husband and her child saw her like this. But still she did not die.

Late one night I was concerned for her and rang the ward from home.

How is Jeanette?" I asked, hoping that she was resting peacefully.

She is crying," the nurse told me.

At that moment I felt that her suffering was too great. I felt overwhelmed by her suffering. I felt that I wanted to go back to the ward and give a sedative injection which was strong enough to end her life and her suffering.

For the first time I grappled with the question of euthanasia. Did I have the moral right to make such a decision? What was my responsibility as a doctor? Did it extend to taking life if the suffering was so great?

It took a long time. But that night I decided that I would never deliberately try to hasten death. I decided that, although I had a responsibility to do whatever I could to relieve symptoms, my intent must always be to relieve the symptom, not to end life. That night I also realised that the suffering I was trying to relieve was also my own and if I was considering ending my patient's life I was actually trying to solve my own problem. I realised that I was treating her suffering as a symptom. I realised that giving medication to end a patient's life is the ultimate form of medical symptom control. I now knew that I too must suffer and I must let go of the need to control my patient's life.

Jeanette's suffering showed me the importance of accepting the

unacceptable and letting life run its course no matter how uncomfortable or how distressing this was for others and for myself.

Instead of giving a telephone order for more medication, I drove to the hospice, gave instructions to the nurses and sat with my patient. Jeanette died some days later.

## LETTING GO

Letting go is so difficult for doctors, nurses and for the patient's family. My last story is about letting go. It is the story of Shaun and of Shaun's mother. Shaun was only eight years old.

The story began one Thursday afternoon when Shaun's parents came to the hospice home care office to ask for help. They told us that their son had a brain tumour and that treatment had failed. One month before, Shaun had been admitted to hospital because his condition had deteriorated very rapidly. They had been able to take him home again but for the past two days he had been semi-conscious and had been unable to eat or drink. When they had rung the hospital doctor, he had said that Shaun must be brought back to the hospital for the insertion of a naso-gastric tube.

They did not want to do this because Shaun had been very clear that he did not want to go back to hospital and he had said that he did not want any more tubes.

The parents were asking what they should do. Immediately I went to the house with them. Shaun was now a little more awake but still unable to swallow. I discussed the options with the parents: intravenous fluids, subcutaneous fluids, nasogastric tube from the nose to the stomach. The difficulty was that Shaun also needed medicine. If he did not get this medicine, how could we prevent fits?

What a difficult decision! On the one hand, they wanted their son to live. On the other hand, they did not want him to suffer and they wanted to

respect his wishes. They also told me that 20 days before Shaun had told them that he had "Only 21 days to go". What an extraordinary thing for an eight year old boy to say!

I suggested that they discuss what to do with Shaun. I said that I would now go back to the office but would come back later.

I came back about 9 o'clock that night. By that time Shaun was sleeping peacefully. They had made a decision. There was to be no intervention. The mother told me that she had explained to Shaun that now that he could not swallow, he would not be able to stay alive without a feeding tube. He had clearly refused to have the tube.

She then told me what she has said to Shaun. But first she explained to me that earlier that year Shaun's grandmother had died. The drugs Shaun had been taking to relieve the pressure caused by his brain tumour had made him very hungry and he had put on a lot of weight. He had been told not to eat the sweets which he craved. But he had told his parents that his grandmother had come to him in his dreams and had been giving him delicious things to eat.

Shaun's mother then told me what she had said to Shaun: It is now time to go to your granny. But remember that we will always want you to be our son. So don't eat too much or we may not be able to recognise you. We will be coming along by and by. If you want anything just tell me in my dreams and when I come I will bring it along with me."

What an extraordinary mother! How remarkable that she was able to let go of her child! How amazing that she was able to let him make this decision! How beautifully she prepared him for what was to come!

Later that night I received a call to say that Shaun was fitting. We were able to manage this in the house and he died the following day. It was exactly 21 days as he had predicted.

This is a story about allowing death to express itself as a natural part of life. This is not euthanasia. There was no intention to deliberately shorten Shaun's life. Shaun and his mother made a decision to allow death to come.

Shaun's mother taught me that children also have the right to know and to choose. She showed me that it is possible to talk of death simply, symbolically but truthfully. She demonstrated real courage in being able to put aside her own hopes and dreams for her son and allow him to face the death experience with integrity.

## ENCOUNTER

Each of these stories is about my own spiritual growth. There are many more such stories. Each one is about specific challenges which deepened my understanding of the world and of myself.

For me hospice has been a painful process, an unfolding, a gradual realisation that what is important is not my clinical skills, not my knowledge of death, dying and bereavement. Instead, I have come to realise that central to the hospice experience is the encounter.

The encounter is not between a doctor and a patient but between two human beings. In that moment of encounter there is a recognition that this experience of dying is common to us all. In the sharing, all we have to offer is truthfulness, being present in the moment, opening our hearts to the suffering and responding with love, often in silence.

Only then are we truly effective. Only then can we allow that person, our patient, to accept the mystery that life and death does have meaning, and that all that they have been has changed the universe for ever.